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Cancer, Technology and and Ineffable Visceral Space

Julian Langer

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occasionally lumped in with (despite having voiced critiqued of both) – anarcho-primitivism and eco-extremism.

With this, I have tried to focus my writings, not on quietist renunciation, but on what it means to Live, while we are surrounded by this Leviathan of death, this cancer, this vile and disgusting machinery. I'd also like to put it here that I haven't embraced anti-civilisation philosophy because I read anti-civ writers like Zerzan, Kaczynski, Quinn or Jenson – though many of their ideas and arguments resonate with my experience – but because what I as-my-body has gone through, both as feeling-what-it-is-to-be-dead and as being-an-Extension-of-the-world-that-is-dying. This is something beyond words and argument; it is the space that you find yourself in after the full stop at the end of the last sentence.

Here I am, committing that faux pas again – the great cosmological-taboo. I love the work by Camus *The Myth of Sisyphus*, though my writing project has been and ones currently in process, have all been reversal of his assertion – whether or not we commit suicide is a rather boring and unimportant question; whether or not we commit Life is the philosophical question that my being feels drawn to. Sure, Life might be weird and absurd and impossible and confusing, but there is an awe inspiring mystical beauty to all of that, which I find to be a desirable place to dance in. Anti-civilisation politics and philosophy is never going to be popular within “society” and is always going to offend those who don't like and don't find resonance with it.

I'm not trying to write something people are going to like – I'm trying to communicate something honest. We are drowning in information, thanks to the internet and TV. There is very little honesty, very little authenticity. If this is a faux pas, so be it.

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they could have provided. Getting through cancer is messy – it is shit, piss, blood, tears and involves being looked at in an entirely naked sense. To survive cancer you have got to put the image you want to have of yourself aside and simply be who the fuck you are in that moment.

We all have civilisation within our being. Many(/most) of us will die from it. It is not a nice comfortable thing to acknowledge, but it is the truth I feel within my body and am as sure of that as I am sure of my own existence within Life, as this mammal who dances mad dances in the woods of Briton. If any of us are going to survive it, it will be those of us who remove our catheters as soon as possible and summon up all the strength they have within them to walk. It is difficult, it is heart breaking, but it is also wonderful, in a weird paradoxical way.

I am not writing this expecting many of you reading this to like it. I am sure lots of you will disregard me as some hypocritical “primitivist” bashing the technology his life has depended upon, through the medium of the internet that wouldn’t exist if he had his way. To those of you who feel that way, I’m not bothered by you not getting it, because I doubt I would if I had not felt the sensations I had done and if your body has nothing similar to draw from you just won’t get it. And if civilisation is what kills you too, I hope your passing is as painless as possible.

Politics has come to seem more and more to be a machine of death, that cultishly worships itself; with its varying factions being different deities within this pantheon. Though less the case than in mainstream-politics, this largely seems the case with radical-politics too, with its endless arbitrary factionalism, call-outs policing of each other and politics-as-fashion. Because I feel a visceral, animal pull of will towards life/power, rather than embracing death, for the most part, while sometimes anti-political, I have tried to keep the bulk of my projects away from politics. This is also the case for the 2 political ideologies I have been

within, I was starting to be able to articulate it, through the book project, through other writing projects and, though it was finding itself less in song and more in instrumentals, through music.

I was aware that I couldn't find another living being doing what this culture does. The badgers, birds, trees and foxes weren't living that cancer, those their lives were obviously impacted by it. And it seems to me, the more I study civilisation, that this is not a "human" phenomenon, but one specifically of this culture.

VIII.

I am still trying to find words to describe this impossible, embodied process to people who might find resonance with this experience of Being-in-the-world. I study loads and write loads, because, to a large degree, the project of my life is trying to scream at the world "YOU ARE FUCKING ALIVE" and as much of what that means, in as beautiful deconstructive, destructive and creative ways as I am able. I don't know how successfully I am doing this, or will ever do it, but it is where my passions are drawn to.

But here is the thing – we don't really have a cure for cancer (and I write that as a cancer survivor, who knows we can kill it). And all our bodies, like the earth we are manifest Extensions of, are infected with civilisation. Technologies might dull the pains and reduce the affect it has, for as long as we have the means to provide those technologies – like the painkillers and steroids I loved and hated in so many ways. Greater more powerful technologies might kill this cancer; but like how radiation therapy could have given me another tumour and still might well make me infertile as an on-going affect on my body, they could well lead to other, potentially worse, horrors. I don't know to what degree the prayers and the crystals, the juices and holistic therapies, the reiki or the meditation, did anything, but I'm not arrogant enough to claim that I know they did nothing and am glad for any part in my healing

I.

I regularly commit what might be considered a severe social faux pas, though it is not really a blunder and I do not feel shame about it. This faux pas is that I mention, often too lightly, in conversation a subject matter often deemed too taboo for everyday conversation.

The subject matter is that which goths, nihilists and existentialists love to talk about – I talk about death.

From my mother's death and my father's near death from drug addiction in my early childhood, as well the loss of other family members and loved ones; death and life have been constant themes within my thoughts. But undoubtedly the biggest influence on my relationship and perspective towards life and death has been the experiences I went through as a young cancer patient.

As I go to write about the process of being-a-cancer-patient, I'm immediately struck by how the words I turn to feel entirely inadequate. If I were to try to really communicate to you (as in you individually reading this, if we were relating one to one) something of what it feels like to be the other side of cancer treatment, I'd probably lower my stance, draw in air and release a guttural and primal scream; then grab hold of you in the tightest, fullest hug I could muster; and then play you something on the guitar. So little of that felt phenomenon can be expressed this way – as-in via text. But I'll go on.

II.

They found my tumour initially because they were trying to find out why I was developing double vision. I first noticed the double vision in its early stages when I watched seagulls fly by the river in the town I live near to. Given the state of British ecology, these birds are forced to live within the built-space this culture has constructed on top of the land. They are an extremely regular sight,

and often labelled vermin by those who do not have eyes to see their beauty.

My eyes were seeing in double. It was weird. It was confusing. Corrective glasses made normal day-to-day activity easier, but why was this happening?

I had my first MRI scan, to see what was going on in my head. What an experience that was! They had to restart the scan because I'd moved too much looking around the scanner as it did its thing.

If you've never been in an MRI machine, let me paint you a picture in words of my times in MRI machines. First thing you do is you lie on this platform, positioning yourself so your head rests in the slot designed for it. Then they place this grey-thing under your knees, so your legs are slightly raised throughout. You then feel the platform rise towards the ceiling, stopping when you are level with the opening of the machine. Your head then gets put in this open-box thing, with wadding to make you more comfortable, and you are handed something to squeeze should you need the process to stop or attention for any other reason. Then you feel yourself moving backwards into the machine, into silence. This is a hideously uncomfortable silence, where you are fully aware of how uncomfortable your body feels within this colossal piece of technological construction. And it feels as if it would go on forever, but then it starts.

The first time I heard that noise I felt my heart pounding immediately. Everything about this was wrong! If you can imagine all the worst elements of drum and bass, mixed with the worst elements of industrial metal that would be the best comparison I could give. That sound pulsates through your entire body, and it feels like it is the noise shaking the machine with your body inside it. My muscles tightened. My mouth went dry. The first time I couldn't stop looking around to see if something was going wrong – as I said, they had to restart it and begin again because my moving had meant the scans were unusable.

full of madness. I'd found a space that I shared energy with, and, though it was in so many ways horrifying, as I studied with increasing intensity the ecological situation and what that entails, I found myself increasingly energised and more passionate about living as furiously as possible.

One night, as I was starting on the first draft on *Feral Consciousness: Deconstruction of the Modern Myth and Return to the Woods*--a work that was largely me trying to put words to this sensation I had undergone--the words I had received through the studies I was engaged with at that time – I spent several hours reading articles and watching talks on “diseases of civilisation”, which includes, as you might have guessed, cancer. Weirdly enough though, this didn't make me feel angrier about civilisation or about what I had gone through as a cancer patient, in any way that might immediately seem logical. That unworded, visceral, animal and entirely defiant energy within me was burning in a way that felt beautiful to me.

What became apparent to me was that civilisation is a cancer and that cancer's manifest form, as a phenomenon, is technology: the technology that is keeping people alive is also killing them. Two things can happen with cancer – either it kills you, or you kill it. If I kill it, like I had done before, then I survive and keep living. If it kills me, then my body will become something else, something the cancer has no way of affecting. This was a strange but wonderful realisation to have. It was neither hopeful, or hopeless. Whatever happens, regardless of whether you have cancer or not, you and I are definitely going to die, which is ok, because we grow into new beings, still very much part of life.

It all felt absurd, but beautifully absurd. Horrific and ugly, but also something I wanted to grab at and bite into. That ineffable visceral energy, whose Wild burnings I'd felt throughout all that time going through treatment, like some skilled fish who lingers just below the surface ready to strike at insects or birds who come to close, that nameless energy, born out of the paradoxical dark-mysticism of the impossible limit-experience I had found myself

lots of love and support from people around me, in particular from Katie. This gave life more beauty during this horrific time. I then started re-reading existentialist philosophers, in particular Camus and Nietzsche, and took creativity in the face of all the meaninglessness around me to be my pathway. And I began to find value in what had happened, knowing that I was in many ways stronger for what had happened, though forever changed.

I started at the same time my undergraduate degree in social psychology and philosophy, and putting myself out into the world as a singer-songwriter. As I explored these spaces I found myself within, delving both into my studies and my creativity as a musician, I found myself drawn towards the weird, the fleshy and the wild, in ways that I couldn't put to words, but that fitted this sensation I had been undergoing.

After the first year post-treatment I was doing well. I'd started exercising more and the body I am was feeling more and more like me. My degree was going very well and music was bringing me lots of joy. I was beginning to find a vocabulary to articulate something of what I was aware of but could not say, not out of taboo, but because it felt beyond the words.

I read Heidegger's *The Question Concerning Technology* and was exploring existentialist ideas on authenticity and inauthenticity, which was the closest thing yet to the feelings I had undergone and the awareness I had of myself within the world. I explored this alongside poststructuralist ideas on hyper-realism and the self as an object constructed through the technology of language. I began to explore philosophy of technology and found resonance with philosophers like Zerzan and found rekindled a visceral childlike love of what is Wild and living. And as my body grew stronger, I would walk more and more through the woods that surround me in the British countryside, listening to the birds as often as I could hear them. Aesthetically, I've always been drawn to music that conjured images of Wild "natural" spaces, with poetry of living-beings, and works of art that are of non-domesticated scenes and

Not in my first time, but in the vast majority of scans after that, they'd stop halfway through, to inject this dye through a cannula I'd already had put in place, so they could track everything better; then to return to the shaking booming machine. Sometimes you're given headphones and they put music on, but I've never heard it over the mechanical thumps in the belly of those things. An energetic, visceral surge desiring escape flowed through me, which remained the case throughout every other time I found myself inside one of those machines – though I eventually learnt to get myself very Zen in them and to ignore what was going on around me.

The day after this first scan, my 19th birthday, I went in to get the results and a doctor informed me that the scan had found a pineal legion, a brain tumour, which at this stage couldn't be confirmed as cancerous, benign, or what. What followed for the next year and a half was months of regular MRI scans, the occasional lumbar puncture and waiting for the tumour to grow large enough to get a biopsy of; because it was too small and they didn't want to risk damage when all it was doing at that stage was moving my eye.

III.

I had been practicing Buddhism since I was 17 and I turned to this heavily during this time, as well as throwing myself into creative projects. The waiting period was strange. I'd been a study-geek since I was a kid and I continued to find myself drawn to studying all I could find on philosophy, radical politics and "spiritual" stuff. Life continued as normal in many ways. It was just always there, as this ever-present thing.

A friend performed reiki on me, which was weird. Christians and Muslims who knew of me having a brain tumour prayed for me. The tumour was growing still, but at an incredibly slow rate – which meant it was still too small for the neurosurgeons to do a

biopsy of it. Was this “spiritual” stuff contributing to this? I didn’t know, but fuck it, I wasn’t gonna knock it!

As I mentioned, I was embracing a Buddhist practice at that time in my life – though possibly a more westernised form than many of you reading this will view as true-Buddhism. I would meditate semi-regularly and occasionally chant. My recovering addict father had pushed the idea on me throughout my childhood than everyone “needs” some form of “spirituality,” and for a time I had largely internalised this notion. This conflicted though with the writers and philosophers I was finding myself drawn to; individuals like Wilde, Nietzsche, Camus and Armand; as what I was getting from their writings were words that fuelled my fire to rebel against this push from my father.

So in place of his Christianised Buddhism, I adopted a much more (indifferent-)agnostic Buddhist practice. Before my embracing a Buddhist practice I had explored Christianity, Islam, Judaism, Zoroastrianism, Taoism and Neo-Paganism (with a consistent solid interest in Hinduism, but didn’t consider practicing until after treatment- and only for a short period), but none of these really stuck as long as Buddhism did and that was what I was embracing during my time as a cancer patient.

My father and I have always had a strained relationship, with him consistently pushing the idea that I should forgive him for his part of our relationship, because if I don’t I will suffer, as I go to hell/have a hellish life for not forgiving him – gosh darn it, don’t you just love Christian morality! With this, he asserted on multiple occasions when my treatment actually started that he believed that, because the tumour was a pineal lesion, and some “spiritual” people have called the pineal gland the gateway to the third eye, that I had the tumour because I wasn’t a more spiritually-forgiving person (though I strongly suspect he was simply pushing for me to be less pissed off at him, so if I did die he would feel like at the very least we had made peace and he could feel like a decent dad).

society being made up of people distracting themselves from death and doing all they could to avoid it all day every day. The more I did the more it all appeared to be one noisy MRI machine; one giant radiation therapy machine; one catheter up everyone’s dick.

Everyone was a cancer patient and everyone was--like all those people who go to cancer hospitals, have the best care in the entire fucking world and don’t make it--going to die. This was an all-consuming thought. And really, what was the point of it all? Why had I bothered to go through all that, if it was just going to be a less intense version of that for the rest of my time alive? Why not just kill myself? I would never be anything of who I was before – I’d always have the tube in my brain and knew I’d never see the world the same again. The Buddhism I had embraced for years was feeling more and more like a lived suicide; a denial of my life through trying to lose my attachment to this body that I am and that I had just gone through so much to keep alive. I contemplated suicide, a lot. I thought of what it would be to just not exist.

All “spirituality” grew less and less beautiful, and seemed more like a technology of flesh renunciation, as I found myself increasingly within-my-body. For a short period I explored Hinduism, but the more I did I found myself trying to find meaning in this space that just didn’t resonate with me (though perhaps was the religion that best mirrored my experience). I’ve always hated asshole “humanist” atheists, who are often more dogmatic than most religious people, and didn’t want to reject what might be beautiful in religious stuff. But I knew that that stuff was no longer for me. It all felt like part of the same life-of-death this culture was looking increasingly like to me, and I wanted to embrace as little death as possible. (Perhaps if my father had been different I’d have a different relationship with this stuff – but that would be a different me and a different world, so I can never know.)

Something un-worded, visceral, embodied and entirely animal kept me from doing anything like attempting suicide. During this time I was still playing a lot of guitar and writing songs, and I had

VII.

As I go to write about this now, I'm aware of my body tensing and I'm thinking more about my breath and what my eyes are doing in their sockets. This is very much a space where I have always found the idea of trying to put words to it something I couldn't do. This was a space of finding myself in the dark-mysticism of what philosophers like Bataille, Foucault and Lacan have called limit-experience. This space is probably the closest I've been to the impossible and probably the closest I'll get to the impossible.

If this comes across as non-sense to you, what I'm about to write, that is ok with me – if you haven't experienced this you most likely simply won't get it. This period, the months immediately after treatment, around my 21st birthday and immediately after; this was a point of falling into a schism, whose abyss seemed like it was going to consume me. I kept this very, very private at the time, as I didn't want to upset those who had supported me throughout the proceeding months and who had done all they could to keep me alive. It felt like utter madness, where I was split between contradictions and caught between monoliths. This wasn't feeling depressed or sad but something like being both caged and liberated, will also climbing and falling.

I'd thought about suicide a fair bit during my mid-teens, but mostly in a distant sense. The time I considered it most was in the months immediately following treatment. Why? Well to answer that I have to start a little before this period.

As I was going to and from between radiation therapy appointments, watching people in their cars from my seat as we drove past them, I would often think about them going to work to get money to buy food and pay for everything they needed to stay alive. I would also think about them feeling exhausted from work when home, watching TV and sitting on their smart phones playing games and tweeting crap they didn't really care about. I would think about this over and over and over again. I would think about

Let me take a second to say though that, in many ways my father was a great dad during treatment, pushing to get me the best care and driving long distances to appointments and lots more. But if I'm going to write about how cancer affected my perception of the world, life and death, I have got to write about how he pushed that the tumour was basically my fault and I had to get more "spiritual", as he saw it, in order to not die (but this piece is not about him or my relationship with him). Moving on.

IV.

Before treatment actually started I'd had this headache for 3 days. It wasn't too bad and I wasn't worrying, but worried family pushed for me get an emergency appointment to see my GP, so I did. At that stage they weren't worried about the headache. But a few days later I'm in A & E with a migraine, being given the steroid dexamethasone to reduce the pressure the tumour was putting on my brain – now the little fucker was getting interesting and starting to kill me.

Suddenly shit got different! Suddenly I was back and forth between appointments. Everyone wanted to keep Julian alive.

Julian however was mostly focused on sleeping and eating. Dexamethasone had two side effects, both of which I found near unbearable; I couldn't sleep and I was always starving hungry. Stress and having lots to think about still has an impact on my sleep patterns, but with the meds at this time I was getting three hours maximum most nights – there was lots of watching TV throughout the night, trying to fall asleep to it. And the hunger, words are entirely inadequate for describing the depth of the hunger I was feeling. This wasn't *"I've missed a meal and now am more hungry than I would normally be at this time"* hungry! This was *"I am screaming at you to put food in me or else you will fucking die asshole"* hunger; it was a hunger that felt like there was an emptiness within my be-

ing that was going to collapse in on itself if I didn't eat something. So you better fucking well believe I ate! Salad sandwiches multiple times a day, fajitas, crisps, pasta and SO MUCH CHOCOLATE ICE CREAM YOU WOULD NOT BELIEVE ME IF I TOLD YOU! (I owe a great deal of my mental well being throughout the months of dexamethasone and afterwards to Ben and Jerry's Half-Baked ice cream).

While so much around me was about keeping me from dying, I was consumed by the suffering this medication I had been put on to keep me alive was bringing me. It was only in the months after treatment that I started to value that experience of suffering – but I'm jumping ahead of myself.

My first night sleeping in a hospital for observations was a new experience for me, one that I did not want, but went along with because the doctor I was under the care of at that point had insisted on it, despite my obviously finding the idea extremely upsetting. I'd seen my mother die in a hospital bed when I was 7; and I'd stood there screaming at her body for her to wake up and to be my mum again. Years later I learnt she died because the hospital made an administrative error and she could have survived what happened to her. To my mind, hospitals meant death. Those cold, sterilised walls and floors felt like lifeless expanses that something entirely visceral inside of me was rejecting, in a very primal way. But as I said, I did it. I slept there, or at least tried to, and made it through until the morning.

The next day I asked the doctor if I could start coming off the tablets, because the headaches had gone and I wanted the suffering to end. Without properly understanding what they were doing and in an utterly careless fashion, he stated yes and gave me an incredibly short weaning off period to come off them – which I accepted because, here was the professional saying what I wanted to hear. Days later I was rushed to hospital (a different one to the one I'd slept at) with an excruciatingly painful migraine and in a zombie like state of lifelessness and put straight back on the dose

I had a month between my last brain surgery and starting radiation therapy. That month involved mostly listening to music, watching TV, playing guitar, eating (LOTS), sitting in the garden and the occasional outing to shops or town, if I felt well enough to do it. I was exhausted though. It took me 3 attempts to stand up from the toilet one morning. The thing I kept saying to people was that I just wanted to go and walk outside. That primal urge to move my body across the land was something I felt deep within me, but at that time I simply couldn't. That was something deeply upsetting and frustrating. My body, the being that I am, felt like something other than myself, but equally I was consumed by this-is-me-now – and I had to deal with that.

I knew I was alive and that was valuable. I felt like death, but knew that this process was transient and I would soon be a different space and in a different space.

Radiation therapy was weird. The first thing I remember them doing was making me this mask to hold my head in place on the table – a mask I kept after treatment ended and have a solid love/hate relationship with. For a month I would go to the hospital 5 days a week every morning; lie down on this table, in front of this colossal machine that looked straight out of science fiction; have my head locked in place by the mask; have radiation beams fired at my head, which you cannot see, hear, or smell, but after the first week or so start to feel the effects of; and then go home, and spend all day resting, playing guitar, video games or watching TV. The day my hair fell out sucked! I was in the bath and it all just started to come out in clumps – it felt much more like losing a part of myself compared with when it had been shaved off 2 months earlier (that was (kind of) my choice at least). But the real impact of radiation therapy didn't start until after cancer treatment had ended, in the months immediately after – a period of time I have barely spoken about with anyone.

was continuing to be a great pick me up. But what helped me the most through those weeks was something entirely beyond words.

Between her university classes and exams, my girl friend Katie, then of 5 years (now wife), was doing all she could to be there for me and be loving and supportive. The experience of love I got from her was more than just words and deeds. There was an energy I could feel in her touch, as she held me with my head on her lap, not judging as I wept uncontrollably. Whether we were watching TV or talking to family, her arms around me communicated an intention that rendered all words as lesser. One night she washed me as I sat in the bath and the love and care I felt her hands communicate made all language slip away into an abyss that left me in bliss. Amidst all the horror that was going on around me, all the suffering and shit I was going through, here was something completely wonderful, that brought the beauty of life and experience back to me in a direct and immediate way. As much as her actions were beyond words, my descriptions are entirely inadequate. You will never be able to know the energy that was felt between us in those moments (and honestly that is something I am glad of).

The second lot of brain surgery was quicker than the first and in many ways a lot easier. I spent most of my stay on ward consuming that beautiful hyper-real spectacle that we postmodern 21st century westerners remain addicted to: TV. No catheter! And was again able to walk afterwards faster than expected. The thing that was the best part of my second brain surgery was that the biopsy had found out the type of tumour that was in my brain.

If you know anything about pineal germinomas (also know as germ cell tumours), you will know that, as far as brain tumours go, being told you have one is extremely good news! These tumours are very easy to treat; they don't often come back; and really this was confirmation that I was going to kick cancer's fucking arse and live beyond this hellish ordeal I was going through! This was the best news yet and everyone around me was glad to learn this.

I'd been on, along with another steroid to help my endocrine system recover from the "crash" in hormones I had just undergone. I'd very, very nearly died and felt like death – the doctor fucked up and I never saw him again.

V.

It was a strange feeling, nearly dying, and coupled with the lack of energy, because my body was void of nearly all the testosterone, adrenaline and cortisol I usually had flowing through me, I felt like a nothingness, empty and soulless, with all my personality sucked out of me. It wasn't that I felt depressed, or sad, or anything like that. No! That would have been something – even when I felt sad and depressed I felt alive. This feeling was death.

Being back on the steroids perked me up, a bit. I was still exhausted and not-all-there, but I was more me, which was something at least. That same visceral feeling I would have with the MRI machines I had with the meds. They were entirely undesirable, but they were working and doing what I needed them to do. Taking them was a choice made for my personal welfare and I am selfish about my personal needs.

Shortly after this though came the second close brush with death. I was taking the medication, but had a mind-blowingly bad migraine. This one was more intense than the others had been. This was pain I couldn't have imagined feeling. I didn't want to move, so tried to sleep it off. This didn't work and pretty soon the paramedics were at the house and I was being carted off to the hospital.

The painkillers I had at the hospital went down an absolute treat! I was the happiest I'd been in a long time! Everyone around me was panicked and trying to work out what to do with me. Calls were being made between hospitals, my father and girl friend were terrified and loved ones were being called with updates on how I

was doing. And while all that movement was going on around me, I was high and happy.

Hours later and a journey from North Devon to Bristol in an ambulance, I found myself on the neurology ward of Frenchay hospital, having my surgery plans explained to me by a lovely old hipster brain surgeon (with a brief chat about mutual music loves). I asked what general anaesthetic would be like and was told “like a good gin and tonic.” I was on the bed, about to go into the theatre room, and told they were about to put me to sleep. There was a moment when I was aware of them administering the painkiller and then I was awaking in the recovery ward.

When I woke up there were two definite differences to my body from when I’d gone to sleep. The first I was prepared for and had expected. The surgery I had was called an endoscopic third ventriculostomy and involved them placing what is called a ventricular reservoir in my head – basically a tube in my brain and a silicone bump on my head to protect me from potential future hydrocephalus. This is something that I have in my head still 6 years on and will most likely have until the day I die. I have often joked about being a bionic human, with my body forever changed by technology. I’m not going to lie; it is very weird to think about – but I’ll write more on this later. All that mattered at that point was – I am alive and this is gonna help keep me alive! The second difference, though less permanent, was far more traumatising at the time.

VI.

Soon after waking I came to discover a tube attached to my bed that had not been there before. After a brief investigation of the bed and my body, I came to realise the tube was inserted somewhere I had never EVER expected to find a tube! (If you haven’t guessed already, they’d inserted a urinary catheter). THE HORROR! I don’t

mind telling you that my penis is something I value and treasure, for a multitude of reasons, and have degree of aesthetic preferences around its appearance and treatment, which includes not having a tube up it. There was an element to which it was apparent, the doctors had seen my naked body, in a way I had not considered before, which, given the amount of body-shame I felt at the time was a bit embarrassing. But more so, again in a very visceral, animal and primal embodied sense, I DON’T WANT A TUBE UP MY DICK!

Hours after waking up, when I felt like I had enough energy to walk a little bit and had shown I could move my legs, I asked the nurse to remove the catheter, so I could walk up and down the ward. She held my member and then moments later I felt a sensation in my dick that makes me squirm and recoil in disgust still, as I write this. After a minute to recover from what just happened, I started to get myself off the bed. A nurse from Somalia, whose kindness throughout my stay on that ward I will value for the rest of my life, held my arm as I walked the corridor from one end to the other. No one thought I’d be walking that quickly, but I was defiant and knew I was going to do it – I knew that this body that I am wasn’t going to just lay in bed with a tube where no tube should be; I was going to walk, and fuck anyone who said otherwise.

After the surgery I spent several days and nights on ward and then came home for a few weeks rest, before I went up to hospital for the second and hopefully final lot of brain surgery. This was a weird time. I felt in many ways ruined, especially the day the last of the general anaesthetic wore off and I couldn’t stop crying. I had my head shaved, because where they’d shaved a rectangular block out of my long fringe looked ridiculous, and that was a particularly sad moment, as I’ve always love my hair. I was low energy, because of my hormones and what it was taking out of my body to recover from the surgeries, and still starving hungry all of the time. I had started seeing regularly a craniosacral therapist and the holistic treatment was definitely helping me sleep, which was a plus, as well as supporting my recovery in other ways. Chocolate ice cream